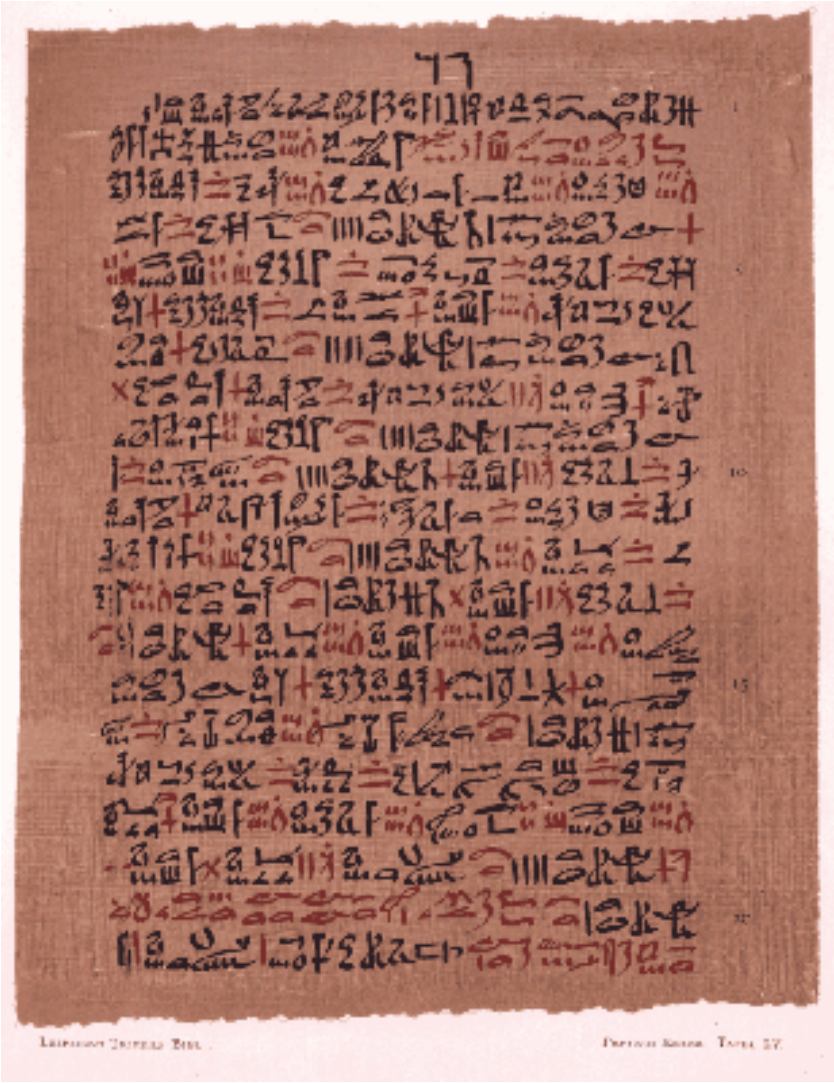
Nutritional Blood Monitoring in Enterally Fed Children with Neurodisability

Dr Andy Barclay

Consultant Paediatric Gastroenterologist
Glasgow UK



Papyrus of Ebers 1550BC ‘try to eat some fresh vegetables’

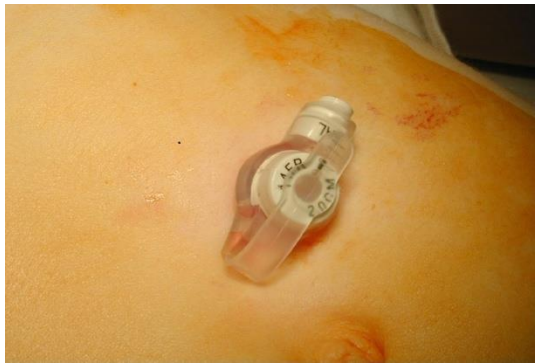
Glasgow: 3600yrs later

EN

‘Artificial’ feeding

- Enteral tube feeds
- Supplements

- Home enteral tube feeding (HETF)



Nutritional Monitoring

- Risk factors for nutritional monitoring
- General evidence
- Bone related issues (newer evidence)
- Jejunal feeding
- Blended diet

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Growth in Neurodisability

- Inadequate intake in CP is highly prevalent[1]
- Growth correlates with severity of disability[1]
- All outcomes improved by nutritional status[2]

1. Reilly S et al *Journ Pediatr* 1996;129:877-82
2. Fung EB et al *J Am Diet Assoc* 2002;102:3-73

Macronutrient profiles

- Lipid predominant [1,2]
- Inadequate Carbohydrate and Protein [1, 2]
- >50% <80% recommended intake[1]
- Inadequacy greater with age[2]

1. Kilpinen-Loisa P et al *Acta Paediatr* 2009;98:1329-1333
2. Lopes PAC et al Rev Paul Pediatr 2013;31:344–349

Indications for EN

Neurological impairment

- Cerebral palsy
- Hypertonicity associated with cerebral palsy
- Traumatic brain injury

Greater than average nutritional requirements

- Chronic lung disease
- Cystic fibrosis
- Complex congenital heart disease

Short bowel syndrome

- NEC
- gastroschisis

Other

- Failure to thrive
- Severe GORD
- Postpyloric feeding requirements
- Nutritional deficiencies
- Motor dysfunction

Conway, S., Morton, A., & Wolfe, S. (2010). Enteral tube feeding for cystic fibrosis (review) cited in Hannah and John (2013) Journal of the American Association of Nurse Practitioners.

nutrients

MDPI

Article

Standard Polymeric Formula Tube Feeding in Neurologically Impaired Children: A Five-Year Retrospective Study

Valeria Dipasquale, Maria Ausilia Catena, Sabrina Cardile and Claudio Romano *

Nutrients 2018, *10*, 684

Standard polymeric feeds

Table 2. Nutritional parameters of children at baseline and at 6 and 12 months after gastrostomy.

Disease	Measurement	Baseline (*N* = 38)	Visit 1 (*N* = 38)	Visit 2 (*N* = 38)	*p*
Cerebral Palsy	Body weight, *N* (%)				
	<−2.5 *z*-score (<5th centile)	18 (64.29)	10 (35.71)	1 (3.57)	<0.001
	−1.8 *z*-score (5th centile)	10 (35.71)	10 (35.71)	5 (17.86)	
	−1.5 *z*-score (10th centile)	0	8 (28.57)	22 (78.57)	
	BMI, *N* (%)				
	<−2.5 *z*-score (<5th centile)	28 (100.00)	20 (71.43)	0	<0.001
	−1.8 *z*-score (5th centile)	0	8 (39.57)	2 (7.14)	
	−1.5 *z*-score (10th centile)	0	0	26 (92.86)	
	Triceps SFT, *N* (%)				
	<−2.5 *z*-score (< 5th centile)	28 (100.00)	10 (35.71)	2 (7.14)	<0.001
	−1.8 *z*-score (5th centile)	0	18 (64.29)	10 (35.71)	
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Nutrients **2018**, *10*, 684

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Nutrients **2018**, *10*, 684

Oro-motor considerations

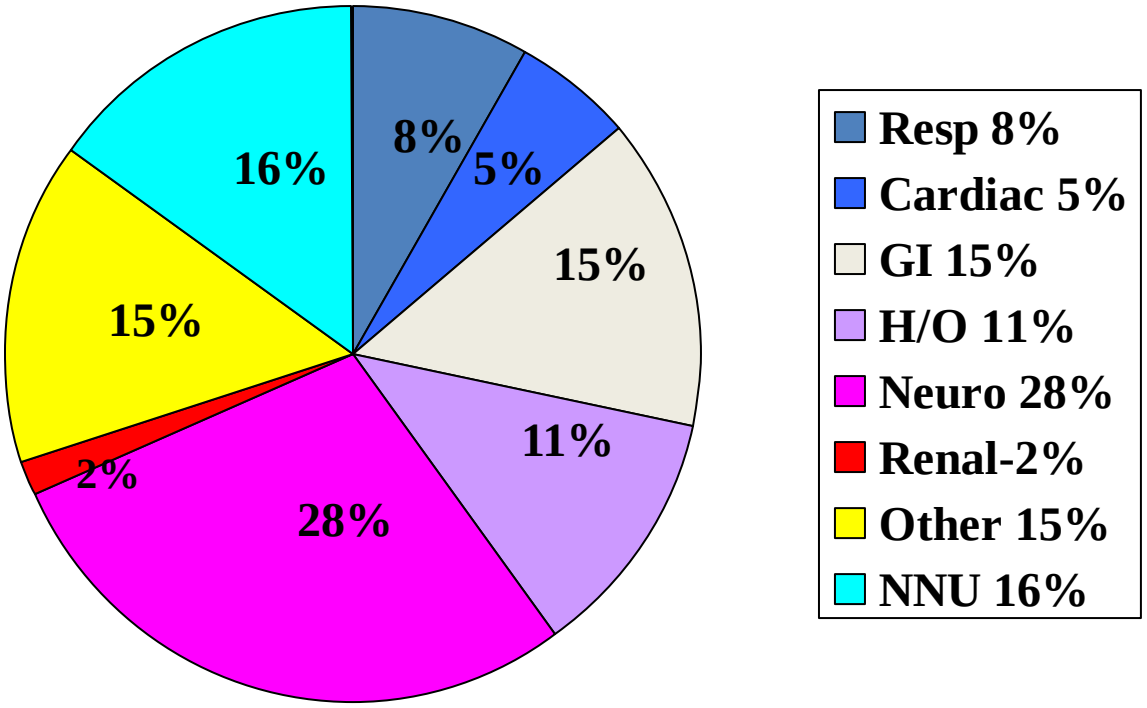
Table 1. Key questions to ask parents for assessment of feeding/swallowing problems in children with cerebral palsy

Questions	*Red flags*
How long does it take to feed your child?	More than 30 min, on any regular basis
Are meal times stressful to child or parent?	Yes, if one or other, or both
Is your child gaining weight adequately?	Lack of weight gain over 2–3 months in young child, not just weight loss
Are there signs of respiratory problems?	Increased congestion at meal times, 'gurgly' voice, respiratory illnesses

Oral feeding often time consuming and stressful for family and severely neurodisabled child[1]

1. Sullivan PB et al *Dev Med Child Neurol* 2004;46:796–800

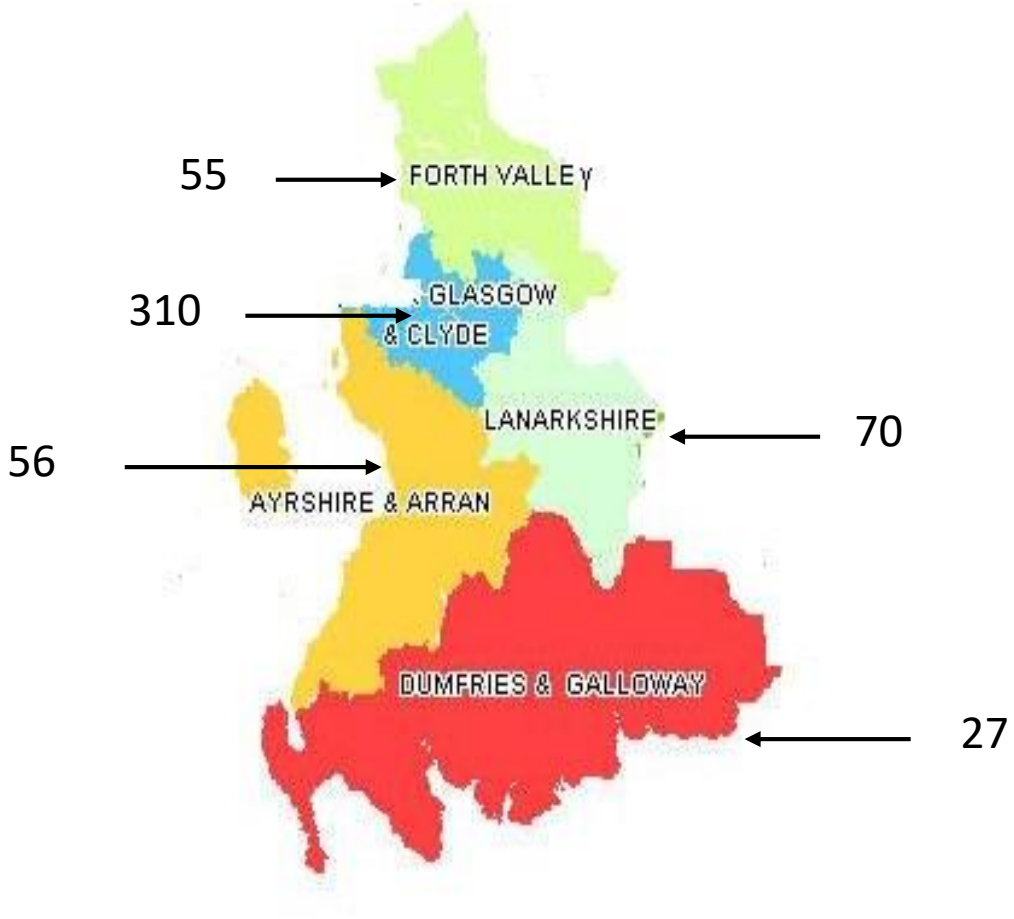
HETF Diagnostic Categories 05.97-05.12 (n=1133)



Overall 41% neurodisabled

South East Scotland Paediatric HETF data, with permission Paxton C and Wilson DC

West of Scotland



Total Number of Paediatric Patients in West of Scotland on HETF = 518

Nutritional Monitoring

- Risk factors for nutritional monitoring
- General evidence
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European Society for Paediatric Gastroenterology, Hepatology and Nutrition Guidelines for the Evaluation and Treatment of Gastrointestinal and Nutritional Complications in Children With Neurological Impairment

*Claudio Romano, †Myriam van Wynckel, ‡Jessie Hulst, §Ilse Broekaert, ||Jiri Bronsky, ¶Luigi Dall'Oglio, #Nataša F. Mis, **Iva Hojsak, ††Rok Orel, ‡‡Alexandra Papadopoulou, §§Michela Schaeppi, ||||Nikhil Thapar, ¶¶Michael Wilschanski, ##Peter Sullivan, and ***Frédéric Gottrand

(*JPGN* 2017;65: 242–264)

TABLE 3. Blood laboratory variables included in the assessment of neurologically impaired children

Urea and electrolytes
Creatinine
Glucose
Full blood count
Hemoglobin, mean corpuscular volume, ferritin, iron
Calcium, magnesium, phosphate
Albumin or total protein
Liver enzymes
Vitamins A, B12, D, E, folic acid
PTH
Zinc

(*JPGN* 2017;65: 242–264)

Best Practice Statement ~ *September 2007*

Caring for children and young people in the community receiving enteral tube feeding

QIS

The importance of communication and sharing of information between local and regional services is key to ensuring best practice for these children and young people

QIS Statements

1. Assessment and support
2. Planning and coordination prior to discharge
3. Equipment and supplies
4. Gastrostomy/jejunostomy care
5. Oral care
6. Tube feeding at school
7. Follow-up care

WoSPGHAN

WoSPGHAN MCN

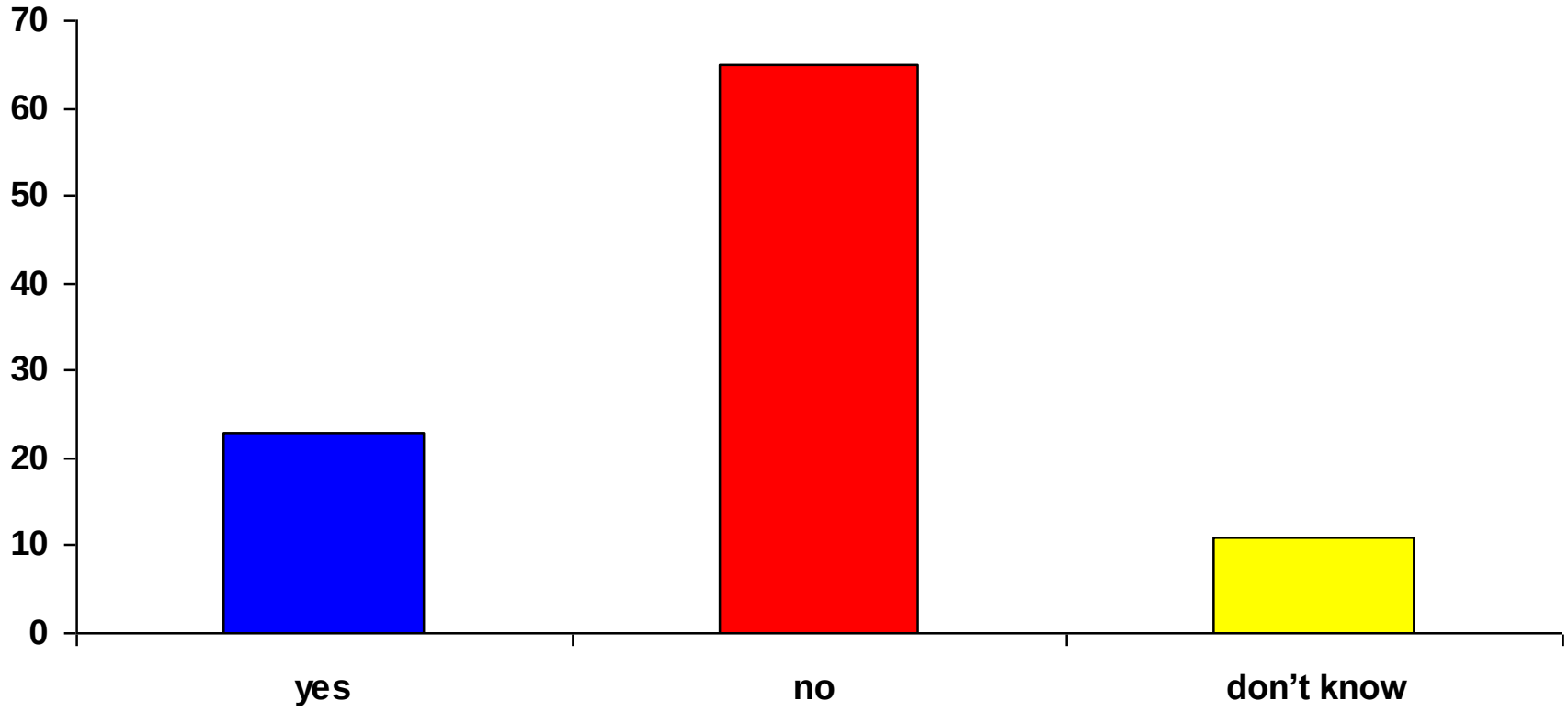
Survey Monkey

Section 7: Follow-up

Children need regular review of their care by the responsible clinician

Assessment includes weight, height, Ofc, equipment and supplies

Documented evidence of long-term plan

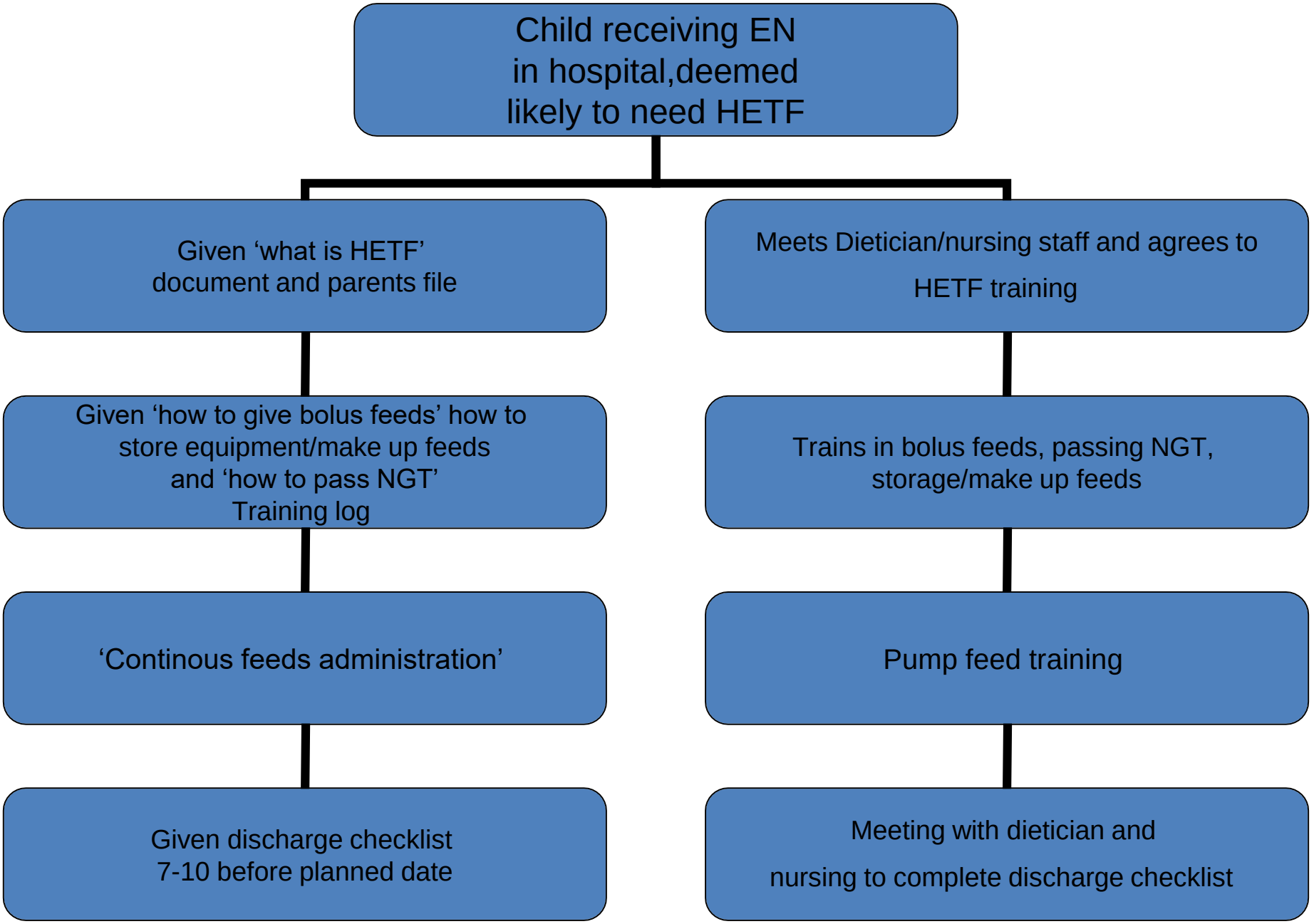


Do you have a pathway in place for monitoring children on enteral feeding?

What isn't working well?

- We need to formalise the monitoring of growth weight and bloods in the community. We need to decide whose responsiblilty this.

- Patients on very long term feeding, are perhaps not as well supported/followed up as they should be
- No annual reassesment of competencies
- No standard patient information, different members of community team may issue different information, not only to patients but also to schools
- No designated pathways


Child receiving EN in hospital,deemed likely to need HETF
Given ‘what is HETF’ document and parents file
Given ‘how to give bolus feeds’ how to store equipment/make up feeds and ‘how to pass NGT’ Training log
‘Continous feeds administration’
Given discharge checklist 7-10 before planned date
Meets Dietician/nursing staff and agrees to HETF training
Trains in bolus feeds, passing NGT, storage/make up feeds
Pump feed training
Meeting with dietician and nursing to complete discharge checklist

QIS Report 2007

- Urea and Electrolytes
- Full Blood Count
- C-Reactive Protein
- Glucose
- Liver Function Tests
- Calcium
- Phosphate
- Magnesium

- Ferritin
- Albumin
- Protein
- Trace Elements
- Fat Soluble Vitamins
- Parathyroid Hormone
- Vitamin B_{12}/ Folate

Baseline, 6 months then annually

QIS 2007; www.nhshealthquality.org

Current evidence

- Adult guidelines suggest 6 monthly nutrition blood test monitoring (NBTM).
- Few studies evaluate NBTM in children on HETF.
- No updated information since Quality Improvement Scotland (QIS) report 2007.
- QIS recommendations have not come from evidence based data.

Caring for Children and Young People in the Community Receiving Enteral Tube Feeding Best Practice Statement Sep 2007, Quality Improvement Scotland www.nhshealthquality.org

Aims

- To appraise evidence for the type and frequency of NBTM for children on HETF via systematic review.

- Recommend how any deficit in current literature can be improved.

Brooks M, Paxton CE, Cardigan C, Wilson DC, Barclay AR. *Journ Pediatric Gastroenterol Nutr* 2014(58) Supp 1; S4.

Methods

P	(Population) Enterally fed children
I	(Intervention) Nutrition blood test monitoring
C	(Comparison)
	Change outcomes?
O	(Outcome)

‘Does regular blood monitoring in enterally fed children change outcomes?’

Search Strategy

- *Pubmed*, *Medline*, keyword and subject (MeSH) 1948-March 2014 (repeated Sept 2019)
- 'Child' 'Micronutrients' 'Enteral feeding'
- Combination of 2 search terms
- Search references of primary studies
- Personal collections, abstracts of major meetings

Results

- >6 million hits
- 5380 combination abstracts
- 37 potential studies
- 10 in original review (20 in 2019)

Evidence level	Study type
1	Systematic reviews, Meta-analysis of RCT's, RCT's
2	Case-control or cohort studies, non-randomised interventions
3	Non- experimental studies, surveys
4	Expert opinion

Harbour and Miller BMJ 2001;323;334-6

www.sign.ac.uk

Grading	Criteria
++	High quality well constructed methods, very low risk of confounding bias
+	Well constructed methods, low risk of confounding bias
-	High risk of confounding bias or non-causal relationship

Harbour and Miller BMJ 2001;323;334-6

www.sign.ac.uk

Results

Study	No	EL	Pop	Monitoring
Guimber	27	1-	RCT (15 CP)	Hb, Fer, FSV, TE, Bvits
Schoendorfer	9	2-	CP	Hb, Fer, TE,
Gottrand	64	2-	Mixed pop	Hb, Fer,Transferrin,TE,FSV
Hillesund	36	2-	Low EE CP	Hb, Fer, FSV ,TE, Bvits
Yang	36	3	SBS	Hb, Fer,Transferrin,TE, FSV
Johnstone	12	3	Mixed pop	Hb, Fer, Bvits, TE, FSV, Alb
Mcgowan	20	3	Severe CP	Hb, Fer, TE, Alb, urinary Na
Skelton	150	3	Low EE CP	Hb, Fer, TE, FSV
Ubesie	178	3	SBS	Hb, Fer, TE, FSV, Bvits
Jones	1	3	3yr old CP	FSV

Key; Hb- Haemoglobin, Fer- Ferritin, FSV- Fat Soluble Vitamins (vitamins A,D,E), TE- Trace Elements (Zn,Mn,Sel,Cu), Bvits Vitamin B (1,2,6,12)

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Collated Evidence

Evidence	No of Studies (EL)	Total No of patients
Fat Soluble Vitamins were only low in Short Bowel Syndrome	2 (3)	74/208
'Standard risk' had normal Follow Up bloods	2 (3)	162/162
Low Energy Expenditure were at risk of Trace Element deficiencies	2 (2-, 3)	111/180
Fibre feed affected Fe absorption	2 (1-, 2-)	39/84

Brooks M, Paxton CE, Cardigan C, Wilson DC, Barclay AR. *Journ Pediatric Gastroenterol Nutr* 2014(58) Supp 1; S4.

Discussion

- Paediatric data for NBTM is limited and of low evidence level.
- ‘Standard risk patients’ NBTM may only be necessary annually
- FSV monitoring may not be required.
- ‘High risk’ patients more frequent NBTM.

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Bone related studies

Study	No	EL	Monitoring	Outcomes
Kuter 2017	32	3	Vit D, PTH, Ca, Phos, Alk Phos	27/32 sufficient Vit D
Abulebda 2017	1	3	Vit D, PTH, Ca, Phos, Alk Phos	Single case , hypophosphataemic rickets in elemental feeding
Gonzalez-Ballesteros 2017	117	2-	Phosphate, Alk Phos, Ca, Vit D	Retrospective analysis of hyposphataemic patients
Creo et al 2018	102	2-	Phosphate, Alk Phos, Ca, Vit D	Comparison of biochemical bone disease in elemental and peptide formulas
Aktar Ali 2019	2	3	Phosphate, alk phos , Ca	Hypophosphataemia not Vit D deficient

Prevalence of Metabolic Bone Disease in Tube-Fed Children Receiving Elemental Formula

Ana L. Creo[a] Lisa M. Epp[b] Julie A. Buchholtz[c] Peter J. Tebben[a, c]

Original Paper

Horm Res Paediatr 2018;90:291–298
DOI: 10.1159/000494726

Creo et al

Table 1. Characteristics of children receiving elemental formula (n = 102)

Characteristic	NC (n = 57)	EC (n = 21)	PM (n = 16)	AM (n = 8)	p value
Age at initiation, months	11 (4–31)	13 (7–40)	1 (1–5.5)	10 (7.5–11)	
Time receiving formula, months	11 (7–21.5)	8 (5–13)	4 (3.5–9.5)	5 (3–7.5)	
Feeding route					0.63
Gastric tube	47 (82.5)	19 (90.5)	16 (100)	8 (100)	
Jejunal tube	10 (17.5)	2 (9.5)	0 (0)	0 (0)	
History of prematurity	9 (15.8)	7 (33.3)	6 (37.5)	3 (37.5)	0.13
BMI <3rd percentile or weight downward crossing of 2 percentile lines	30 (52.6)	6 (28.6)	7 (43.8)	5 (62.5)	0.31
PPI use	39 (68.4)	16 (76.2)	12 (75.0)	8 (100)	0.59
Monitoring data					0.32
Laboratory tests and radiographs	8 (14.0)	4 (19.0)	7 (43.8)	2 (25.0)	
Laboratory tests only	18 (31.6)	5 (23.8)	4 (25.0)	1 (12.5)	
Radiographs only	6 (10.5)	6 (28.6)	3 (18.8)	2 (25.0)	
No monitoring	25 (43.9)	6 (28.6)	2 (12.5)	3 (37.5)	
Metabolic bone disease		0 (0)	0 (0)	0 (0)	
Confirmed	4 (7.0)				
Suspected	2 (3.5)				

Values are presented as median (interquartile range) or n (%).

Horm Res Paediatr 2018;90:291–298
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Risk factors for low bone mineral density

Vitamin D, Calcium intake

Malnutrition

Immobility

Poor sunlight exposure

Proton Pump Inhibitors

Anti-epileptic medication

Vitamin D implicated in...

Cardiovascular Disease

Multiple Sclerosis

Malnutrition

Obesity

Asthma

Depression

Rheumatoid Arthritis

Non Alcoholic Fatty Liver Disease

The effect of gastrostomy tube feeding on body protein and bone mineralization in children with quadriplegic cerebral palsy

FIONA ARROWSMITH[1] | JANE ALLEN[2] | KEVIN GASKIN[2] | HELEN SOMERVILLE[1] | SAMANTHA CLARKE[2] | EDWARD O'LOUGHLIN[1]

Developmental Medicine & Child Neurology 2010, 52: 1043–1047

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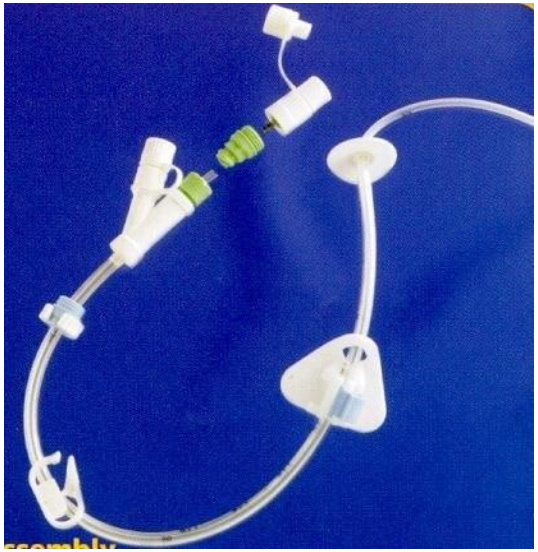
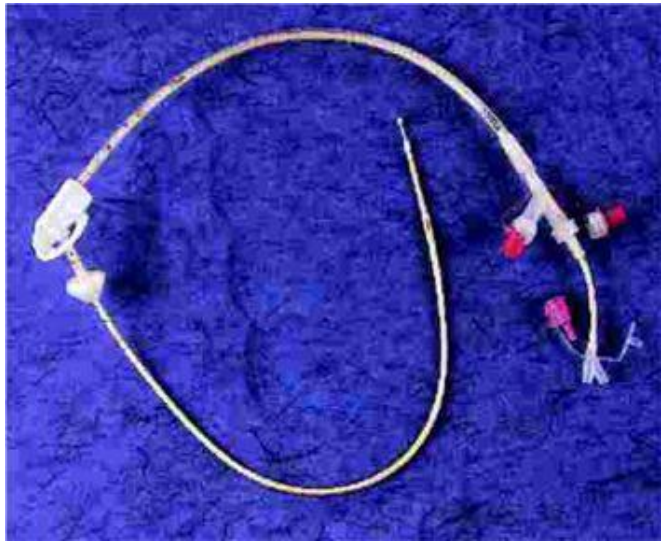
Jejunal feeding – pros & cons

Reduced risk of aspiration / vomiting	Limited distention capability – no storage
Intermediate step before PN	‘dumping syndrome’ effects
Gastric decompression	Increased continuous pump feeding time
Oral / gastric feeding not precluded	Frequent tube replacement secondary to ‘migration’ unless REY

PEG-J



Freka PEG-J



Corpak PEG-J

Barraclough and Cooke

Table 1 A critical appraisal of paediatric papers relevant to the clinical question

Citation	Study group	Study type	Outcome	Key result	Comments
Jayakumar *et al*,[11] 2005, UK	n=1 adult patient fed by jejunostomy due to stricture	Case report	Response to copper supplementation in a jejunally fed patient with copper deficiency.	'Copper supplements in the form of copper sulphate are not adequately absorbed when administered through a jejunostomy tube.'	► Single-patient study. ► Adult patient (age 19 years). ► Describes the intermittent response to intravenous copper therapy and failed response to jejunal copper supplementation.
Hicks *et al*,[6] 2016, USA	n=1 paediatric patient (aged 13 years)	Case report	Association between copper deficiency and jejunal feeding.	Since prolonged jejunal nutrition support is more prevalent in clinical practice, it is important to measure micronutrients (copper and iron).	► Single patient study. ► Paediatric patient. ► Commentary on an experience of copper deficiency in a jejunally fed patient without discussion about treatment and response.
Jacobson *et al*,[5] 2017, Ohio	n=3 patients. Patients included a 9-month-old child, a 16-year-old adolescent and a 20-year-old adult. All three were exclusively jejunally fed with a recognised cytopaenia secondary to copper deficiency.	Case series	Association between cytopaenias and copper deficiency.	'Case series highlighted the need for increased awareness of the risk for copper deficiency in pediatric patients receiving exclusive jejunal nutrition, especially those who develop peripheral cytopenias'.	► three individual case reports ► Two patients younger than 18, one adult. ► No conflicts of interest declared. ► Response to enteral (gastric or jejunal) and parenteral supplementation reported.
Dembinski *et al*,[2] 2012, Florida	n=3 patients. Patients included children aged 14 months, 6 year and 12 years. Two patients were receiving parenteral nutrition and one patient was severely malnourished.	Case series	Association between copper deficiency and parenteral nutrition dependency and malnourished patients.	'With a growing number of parenteral nutrition-dependent patients with short bowel syndrome, it is critical that copper deficiency be recognized and new guidelines be established'.	► three individual case reports. ► All paediatric patients. ► All hospitalised patients. ► At diagnosis of copper deficiency all patients were supplemented with copper at doses between 10–29 µg/kg/d. ► No conflict of interest declared. ► No specific commentary on the product used for supplementation.

Arch Dis Child August 2019 Vol 104 No 8

West of Scotland Copper

- 27/68 patients sampled
- 5/27 one deficiency
- 2/27 deficient on more than one occasion

- Range 1.2- 23.9 (Defic <12.5)

Severe Deficiency

- 1.2 Witzel Jej
- 5.7 Witzel Jej

Deficiency related to distance from Duodenum?

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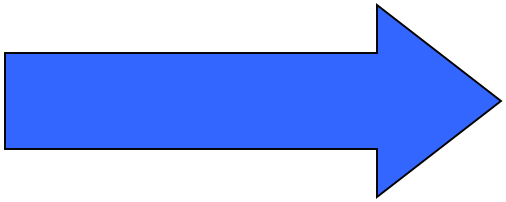
What is blended diet??



Evidence to date

Author	Population	Result
Johnson et al (2017)	433 parents	Fewer symptoms of feed intolerance in BD group Primary reasons BD not used time constraints & lack of knowledge
Hurt et al (2016)	54 OP (HETF, USA)	More natural, eat like rest of family Fewer GI symptoms
Klek et al (2014)	142 paediatric,	Risk of infection, length of stay, number admissions decreased BMI significantly increased
Pentiuk et al (2011)	33 paediatric, post fundo, USA	29/33 gained weight Decrease retching and increased oral intake reported
Santos & Morais (2009)	30 paediatric HETF, Brazil	Stunting increased by 23% Underweight decreased Milk based feeds more adequate than soup based BD
Tanchoco et al (2001)	13 COPD pts, Philippines RCT	No significant difference recorded in outcomes
Kendell et al (1982)	24 adult surgical pts, USA	MAC decreased in un-supplemented group Supplemented pts had higher energy and protein intake

LETTER

Risks of inadequate nutrition in disabled children: four cases of scurvy

To cite De Ioris MA, Geremia C, Diamanti A, *et al*. *Arch Dis Child* 2016;**101**:871.

Table 1 Clinical presentation

Patient no	General signs and symptoms	Gingival	Bone
1	Irritability, anaemia, petechiae	Swelling, ecchymoses and bleeding	Arthralgia, myalgia, joint swellings
2	Irritability, insomnia, petechiae	Swelling, ecchymoses	Arthralgia, myalgia
3	None	None	Arthralgia, joint swellings
4	Irritability, anaemia, petechiae, ecchymoses, appetite loss	Swelling, ecchymoses and bleeding	None

To cite De Ioris MA, Geremia C, Diamanti A, *et al*. *Arch Dis Child* 2016;**101**:871.

Current Inpatient Practice for BD

- MSc project by Sarah Bremner, Paediatric Dietitian at Royal Hospital for Children, Glasgow

- Online survey of 22 UK regional paediatric hospitals
- Lead paediatric dietitians invited
- Response rate 82% (*n=18/22*)

- 11/18 (61%) hospitals permit the inpatient use of BD
- …but 17/18 (94%) of hospitals have had inpatients use BD

Health board	Numbers	CEN involvement
GGC	16	13/16
Lanarkshire	10	10/10
Ayreshire +Arran	4	4/4
Forth Valley	2	2/2
Dumfries and Galloway	1	1/1

Full Blended Diet	**10**
Partial Blended Diet	**23**

Blood Monitoring

- 17/33 NTBM as per QIS doc >6/12 BD
- 10 partial 7 full
- 5/17 all bloods WNL
- 6/17 recorded a deficiency
- 8/17 recorded an elevated level
- 3/17 had both deficiency and elevated

Deficiencies

Patient Number	Diagnosis	BD	Deficiency
6	26/40 NEC and Neurodisability	Full	Low Zinc (mild)
7	HIE, Neurodisability	Full	Low ferritin (severe)
12	Syndromic dysmorphism, mod developmental delay	Full	Low selenium and Vit E (mild)
13	Severe cerebral palsy, pancreatitis	Partial	Low zinc (mild)
15	Severe spastic cerebral palsy	Partial	Low selenium (mild)
16	Preterm short gut	Partial (+PN)	Low zinc (mild)

Yet Again, Serum Zinc Concentrations Are Unrelated to Zinc Intakes

Hennigar S et al *J Nutr* 2018;148:1341-51

Elevations

Patient Number	Diagnosis	BD	Elevation
1	Syndromic severe developmental delay	Partial	Vitamin E
4	Angelmann syndrome	Full	Vitamin A
6	26/40 NEC and Neurodisability	Full	Selenium
7	HIE, Neurodisability	Full	Vitamin E
10	Neonatal haemorrhagic stroke	Full	Selenium
11	Congenital diaphragmatic hernia, mod delay	Full	High B Vitamins , Selenium
13	Severe cerebral palsy, pancreatitis	Partial	Vitamin A, B1
14	Severe dystonic cerebral palsy	Partial	Maganese
17	Mid Gut Volvulous	Partial (+PN)	B Vitamins

Elevations

Patient Number	Diagnosis	BD	Elevation
1	Syndromic severe developmental delay	Partial	Vitamin E
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BD

- At present mostly in addition to ‘standard’ EN
- Micronutrient abnormalities described
- More study of micronutrients needed

Summary

- Micronutrient screening understudied
- Over sampling low risk patients?
- Under sampling known risk factors
- Labour intensive for carers and health professionals

Special considerations

- Co-existent short bowel syndrome
- Low energy expenditure
- Elemental Feeds
- High fibre feeds
- Poly-pharmacy
- Jejunal feeding
- Blended Diet

Ackowledgements

- Hazel Duncan
- Elaine Buchanan
- Sarah Bremner

- Catherine Paxton
- David Wilson

- Michelle Brooks
- Gregor Walker
- Diana Flynn
- James Andrews

Questions?